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# **Anxiety in Young People with Autism Spectrum Disorder (ASD): Common and ASD-Related Anxiety Experiences, and their Associations with Individual Characteristics**

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### Abstract

Anxiety is common in Autism Spectrum Disorder (ASD). Many anxiety symptoms in ASD are consistent with DSM-5 anxiety disorders (termed “common” anxieties), but some may also be qualitatively different, likely relating to ASD traits (herein termed “ASD-related” anxieties). To date, few studies have examined both “common” and “ASD-related” anxiety experiences in ASD. We explored caregiver-reported Spence Children’s Anxiety Scale-Parent version (SCAS-P) data from a multi-site (UK, Singapore & USA) pooled database of 870 6-18-year old participants with ASD, of whom 287 provided at least one written response to the optional open-ended SCAS-P item 39 (*“Is there anything else your child is afraid of?”*). Responses were thematically coded to explore (i) common and ASD-related anxiety presentations; and (ii) their relationship with young people’s characteristics. Nearly half of the responses were ASD-related anxieties (mostly sensory, uncommon or idiosyncratic specific phobias and worries about change and unpredictability). The other half described additional common anxieties not covered in the original measure (mostly social, weather and environmental disasters, and animals). Caregivers of participants who were more severely affected by ASD symptoms reported more ASD-related, as compared to common, additional anxieties. Implications for the assessment and understanding of anxiety in ASD are discussed.

*Keywords:* Autism Spectrum Disorder, anxiety, young people, children, comorbidity, phenomenology, presentation, assessment, measurement.

### **Lay Abstract**

Many autistic young people and adults experience anxiety. Some of the things that make autistic people anxious are also experienced by many non-autistic people (we call these common/ shared anxieties), while some experiences may be more common in autistic and less common in non-autistic people (we call these ASD-related anxieties). Most research so far has used existing measures of anxiety developed for non-autistic people to measure autistic people's anxiety, but much less is known about the more ASD-related anxiety experiences of young people on the spectrum. In this study, we wanted to find out what were the different types of common but also ASD-related anxieties that caregivers reported their autistic children experienced. We used a question in the Spence Children's Anxiety Scale-Parent version (SCAS-P) which asks "*Is there anything else your child is afraid of?*". We pooled together all the responses from caregivers of 870 6-18-year old young autistic people from three countries (UK, USA and Singapore), of whom 287 provided at least one written response to this question. We then organized their responses into common and more ASD-related anxiety presentations: we found that about half were ASD-related (these were sensory; some less common specific fears; and worries about change and unpredictability), and the other half were common anxieties (mostly social worries, anxiety about the weather, environmental disasters, and animals). We discuss how these findings could help better identify anxiety in autistic young people and provide more ASD-informed supports.

## Introduction

High rates of clinically elevated anxiety, anxiety disorders and/or idiosyncratic fears in autism spectrum disorder (ASD) have been recognized since the original clinical descriptions of autism (Kanner, 1943), as well as been consistently reported in recent systematic reviews and meta-analyses in both young autistic people (rates of 30-50%; van Steensel et al., 2011; White, Oswald, Ollendick, & Scahill, 2009) and adults (rates of 40-50%; Buck et al., 2014; for a review see Kent & Simonoff, 2017), as compared to 3-5% in the general population (Bitsko et al., 2018).

Given the high anxiety rates and considerable clinical impact (i.e. Kerns et al., 2015), increasing research efforts have been invested in better understanding the factors and mechanisms implicated in anxiety in ASD (i.e. Rodgers & Ofield, 2018; South & Rodgers, 2017; Vasa et al., 2018; White et al., 2015; Wood & Gadow, 2010; Kerns & Kendall, 2012). Yet, in order to be able to identify anxiety risk and protective correlates and mechanisms, it is first necessary to understand and better characterize and assess the way anxiety is experienced and presents in this population.

The psychometric properties of common anxiety assessments developed for the general child population<sup>1</sup> when used with autistic children and adolescents have only recently started to be examined (i.e., Kerns et al., 2015; White et al., 2015; Zainal et al., 2014; Magiati et al., 2017; Jitlina et al., 2017; Glod et al, 2017; for earlier reviews, see Lecavalier et al., 2014; Wigham & McConachie, 2014). Clinical experience and findings from these studies highlight several complications in their use. Firstly, individuals on the spectrum may respond more intensely, aversively or persistently towards stimuli that appear seemingly harmless or minor to most others without ASD (e.g., Evans, Canavera,

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<sup>1</sup> Commonly employed tools for the general population with good psychometric properties include the Anxiety Disorders Interview Schedule - Children and Parent versions (ADIS-IV; Silverman & Albano, 1996); the Multidimensional Anxiety Scale for Children (MASC; March, 1997); the Spence's Children Anxiety Scale - Children and Parent versions (SCAS; Spence, 1997), and others.

Kleinpeter, Maccubbin, & Taga, 2005; Mayes & Calboun, 1999; Mayes et al., 2013).

Secondly, young people with ASD, particularly those with intellectual or verbal impairments, may also struggle with reporting their anxieties, may express these in less neurotypical or conventional ways, or may find it difficult to verbally articulate their worries, all of which make it difficult for them or their informants to accurately report anxiety (Glod et al., 2017; Hallett et al., 2013). Thirdly, there is overlap between the behavioral symptoms of ASD and symptoms commonly associated with mood and anxiety problems (i.e. Spain et al., 2018; South et al., 2017). Fourthly, factor structures of existing informant-based anxiety measures are generally poorly replicated in ASD samples, suggesting that the measures do not entirely capture the experience of anxiety in ASD (i.e. Glod et al., 2017; Magiati et al., 2017; White et al., 2015; Dovgan et al., 2019). Kerns & Kendall (2012) first theorized about the potential importance to better disentangle common/traditional anxieties from ASD-related anxiety experiences for better identification, diagnosis, and understanding of possible differential underlying processes, possibly leading to more specific, targeted interventions for the ASD population. Current emerging qualitative and quantitative empirical research points out that autistic people often experience fears, worries, and anxieties which are common in the general population and/or those consistent with DSM-5 anxiety disorders (thereafter referred to as “*common*” anxieties), as well as anxieties which are more closely related to their core ASD characteristics and experiences (hereafter referred to as “*ASD-related*” anxieties; e.g., Kerns & Kendall, 2012; Mayes et al., 2013; Bearss et al., 2016; Ozsivadjian, Knott, & Magiati, 2012; Trembath, Germano, Johanson, & Dissanayake, 2012).

### **“Common” DSM-5 anxiety symptoms and disorders in ASD: the evidence to date**

In a recent review of twelve studies investigating rates of DSM anxiety disorders in

a total of more than 1,200 children, adolescents and adults with ASD using clinical diagnostic interviews only (not screening/informant measures), Kent & Simonoff (2017) reported a prevalence rate of any anxiety disorder of around 50%, with large variability between the different studies, depending on the specific clinical interview used and sample characteristics. The most common anxiety disorders were specific phobias (31-67%), followed by social anxiety (4-29%) and OCD (5-37%; no longer included in the DSM-5 anxiety disorders). Generalized Anxiety Disorder (GAD) rates were also variable (6-32%), but much higher than those in the general population and in those with intellectual disability (ID). Separation anxiety rates and panic disorder rates were less common. These rates were in general consistent with an earlier meta-analysis of anxiety rates in young individuals with ASD, in which studies utilizing clinical interviews as well as those using screening informant-based or self-report measures were included (van Steensel et al., 2011; see also more recently van Steensel & Heeman, 2017).

With regards to specific phobias, common in childhood, fears of needles/ injections/ blood/ germs/ doctors, insects and animals were the most frequently reported in ASD (e.g. Leyfer et al., 2006; Muris et al., 1998). Common social worries (i.e. being socially evaluated, not meeting social or performance -related expectations, public speaking and others) as well as common generalized worries (i.e. about school, finances, the future, weather, natural disasters etc.) are also often identified in young people on the spectrum (see Magiati, Ozsivadjian & Kerns, 2017 for a review).

### **ASD-related anxieties**

**Idiosyncratic specific phobias (SPs).** When participants are explicitly invited to identify other specific fears and phobias not included in the DSM or in DSM-derived traditional clinical measures, idiosyncratic or uncommon SPs (e.g. fears of chocolate buttons, men with beards, toilets, fears of specific foods) are more frequently reported in

ASD compared to non-ASD samples (Evans et al., 2005; Gjevik et al., 2011; Witwer & Lecavalier, 2010). Moreover, Kerns et al. (2014) found that children with ASD sometimes show anxious anticipation and reactions towards stimuli that are generally considered enjoyable in childhood (e.g., happy birthday song, bubbles, Christmas), which may be at least partially driven by sensory or social issues or by difficulties with changes in routine (for more on this see next section).

**Sensory-related anxieties.** ASD-related sensory hypersensitivity and associated sensory processing difficulties are consistently associated with elevated anxiety (Ben-Sasson et al., 2008; Lidstone et al., 2014; Wigham et al., 2015). Individuals with ASD with moderate to severe sensory symptoms also have significantly higher anxiety scores compared to those with less severe sensory issues (Sasson, Turner-Brown, Holtzclaw, Lam, & Bodfish, 2008; Uljarevic, Carrington, & Leekam, 2016). Some of the uncommon or idiosyncratic specific phobias reported in individuals with ASD discussed above may likely stem from sensory sensitivities, which in turn may be exacerbated in situations of uncertainty, such as change, transition or overload.

**Anxiety about uncertainty, change, uncertainty and novelty.** 22% of the 59 7–17 year old individuals with ASD in Kerns et al. (2014) presented with anxiety specifically related to changes in daily routines or routes. Rodgers et al. (2016) proposed that many individuals with ASD experience intolerance of uncertainty (also a common factor implicated in anxiety, and specifically GAD, in the general population), and that therefore insistence on sameness and ASD-related repetitive behaviors may serve to impose predictability and to help cope with anxieties associated with change, novelty or uncertainty (Boulter, Freeston, South, & Rodgers, 2014; Chamberlain et al., 2013; Gotham et al., 2013; Uljarevic et al., 2017).



### **The present study: rationale, aims and research questions**

Currently, existing anxiety measures mostly do not enquire about ASD-related experiences and/or expressions of anxiety in ASD (Kerns & Kendall, 2012; Wood & Gadow, 2010). Proposed adaptations/addenda and new measures deriving from, or extending, existing anxiety measures to include scale items that are more relevant to and applicable for the ASD population are being developed (i.e. Bearss et al., 2016) or have recently been developed (Kerns et al., 2016; 2017; Rodgers et al., 2016; Scahill et al., 2019), show preliminary evidence of good to excellent psychometric properties, but these have only just recently begun to be used or investigated more widely.

A small number of focus groups (Bearss et al., 2016; Ozsivadjian, Knott, & Magiati, 2012; Trembath et al., 2012) and clinical interview studies (Kerns et al., 2014; Leyfer et al., 2006; Pearson et al., 2006) have provided valuable data to date in disentangling anxiety symptoms commonly present in the general population from ASD-related anxiety presentations and experiences (e.g. Renno & Wood, 2013; White, Bray, & Ollendick, 2012; Keen et al., 2017).

Furthermore, Kerns et al. (2014) and Ollendick and White (2013) remain, to our knowledge, the only research studies to date to investigate possible associations between child characteristics and common versus ASD-related anxiety experiences and symptomatology. Kerns and colleagues found that higher ASD symptom severity and more anxious cognitive styles were more predictive of ASD-related anxieties, whilst higher anxious cognitive style, better language ability, and higher sensory sensitivity and avoidance were more predictive of common (DSM-related) anxieties. Ollendick & White (2013) reported common in both children with and without ASD anxiety-related processes of negative biases, unhelpful automatic thoughts and physiological arousal, while social confusion, alexithymia, sensory sensitivities and insistence on sameness

were more unique to anxiety in the ASD group.

Adopting a different methodology (analyzing informants' written responses to an open-ended anxiety item of an existing anxiety measure) and attempting to replicate and extend existing findings in the literature with a much larger international pooled sample, the present study aimed to:

(a) Systematically code, organize, categorize, and describe the range of anxiety presentations which were qualitatively different from the common DSM-related anxiety symptoms reported by caregivers in response to an open-ended anxiety questionnaire item of the Spence Children's Anxiety Scale (SCAS-Parent version); and

(b) Explore whether individual child characteristics (gender, age, intellectual and/or adaptive functioning, and autism symptom severity) may be differentially associated with common versus ASD-related anxiety symptoms.

## Methods

### Participants

**Inclusion criteria.** Children were included in the pooled database if they: (a) were 6–18 years old; and (b) had a professional/clinical diagnosis of ASD, Autism, Autistic Disorder, Asperger syndrome or PDD-NOS<sup>2</sup> provided by a qualified mental health or medical professional using the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR or DSM-5) or the *International Classification of Diseases* (ICD-10). Many participants also had additional data from the Autism Diagnostic Observation Schedule (ADOS) or from a screening autism checklist (see Measures, ASD symptomatology). Inclusion/ exclusion criteria for each of the 13 pooled studies can be found in [name of author removed for blind review et al., 2017]).

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<sup>2</sup> Clinical diagnoses of Autism, Autistic Disorder, Asperger's syndrome or PDD-NOS were given as per DSM-IV-TR, as most of the participants were diagnosed before 2013 – when DSM-5 was published.

**Participant characteristics.** The original pooled database from 12 studies in three countries (Singapore, UK, USA; see [name of author removed for blind review et al., 2017 for more details) included caregiver-reported data (74.8% mothers) from 870 participants with ASD (87.7% males; age range 5.58–18.67 years old;  $M = 11.60$  years,  $SD = 2.77$  years; 83.7% reported DSM-IV-TR/ DSM-5 clinical diagnoses of Autistic Disorder or ASD; 12.8% Asperger Syndrome; 3.7% PDD-NOS).

Of the 870 participants in the pooled database, 287 caregivers (33%) provided at least one written response to the open-ended SCAS-P item 39 which allowed us to examine the above research questions. These 287 respondents constituted this study's sample (see Table 1 for participant characteristics). The present study's subsample was generally representative of the full pooled database sample in terms of gender, clinical diagnosis, autism severity; they were somewhat younger and had lower overall functioning classification scores than the full database participants, but effect size of the differences were small (Table 1).

#### INSERT TABLE 1 ABOUT HERE

**Recruitment.** All but 21 participants (who were a clinical sample seeking treatment for anxiety) in the large pooled database were recruited from community settings (i.e. special needs or mainstream schools, parent support groups, clinical referrals for ASD but not anxiety, autism research databases, social skills groups, etc.; see name of author removed for blind review et al., 2017).

#### Measures

**Demographic characteristics.** All 12 studies obtained information on the children's age, gender, and clinical diagnosis.

**Intellectual/adaptive functioning.** Different standardized measures<sup>3</sup> were

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<sup>3</sup> These included the *Wechsler Intelligence Scale for Children – Third Edition* (Wechsler, 1991),

employed in the different pooled studies to measure intellectual/ adaptive functioning in many, but not all, pooled study participants. To facilitate the comparison of cognitive and adaptive functioning data across different measures and scores, an ordinal harmonized “approximate level of functioning” variable was created, ranging from 1 (standard score <40) to 8 (standard score  $\geq 120$ )<sup>4</sup>; see *name of author removed for blind review* et al.

(2017) for a more detailed overview of data harmonization).

**Autism symptom severity.** Different measures of caregiver-reported autism symptom severity<sup>5</sup> were also used in the different studies (n=392 participants). As above for level of functioning, autism symptom severity data from different measures were also harmonized by dividing each participant’s total raw score by the respective scale maximum score to derive raw scores with a 0–1 range (higher scores = more ASD symptoms; *name of author removed for blind review* et al., 2017).

### **Anxiety.**

**Common anxiety.** The *Spence Children’s Anxiety Scale-Parent Version* (SCAS-P; Spence, 1999) is a 38-item caregiver-completed anxiety questionnaire derived from DSM-IV-TR and developed for use with the general child/youth population. Items are rated on a 4-point scale (“Never” to “Always”) and later re-coded from 0 to 3, with higher scores indicating more anxiety (score range 0-114; >24 suggested clinically elevated cut-off for the total score; normative  $M = 14.20$ ,  $SD = 9.70$ ; Nauta et al., 2004). SCAS-P has

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Wechsler Abbreviated Scale of Intelligence (Wechsler, 1999), *Stanford Binet Intelligence Scales – Fifth Edition* (Roid, 2003), *Kaufman Brief Intelligence Test – Second Edition* (Kaufman & Kaufman, 2005), or the *Scales of Independent Behavior – Revised Short Form* (Bruininks et al., 1996).

<sup>4</sup> 8 = standard score  $\geq 120$  (superior); 7 = 110-119 (high average); 6 = 90 – 109 (average); 5 = 80-89 (low average); 4 = 70-79 (borderline); 3 = 55-69 (mild ID); 2 = 40-54 (moderate ID); 1 = <40 (severe or profound ID). These categories were based on Weschler scales classification and DSM-5 ID ranges.

<sup>5</sup> These included the *Social Responsiveness Scale* (Constantino & Gruber, 2005), the 29-item *Developmental Behavior Checklist* (Einfeld & Tonge, 2002) *Autism Screening Algorithm score* (DBC-ASA), and the *Social Communication Questionnaire* (Rutter et al., 2003).

six subscales: separation (6 items), social (6 items); generalized anxiety (6 items), panic/agoraphobia (9 items), specific phobias (5 items), and obsessive compulsive disorder (6 items). The SCAS-P has excellent convergent and divergent validity across age, gender, and countries in the general population (Nauta et al., 2004; Zhao & Wang, 2012). Promising psychometric properties have been reported in ASD, but the factor structure is inconsistent in different studies (Zainal et al., 2014; Magiati et al., 2017; Jitlina et al., 2017; Glod et al., 2017).

***ASD-related anxiety.*** The SCAS-P includes a final open-ended question (item 39; not included in total or subscale score calculations and optional to complete), which asks: *“Is there anything else that your child is afraid of?”* - this item can be rated as “Yes” or “No” and allows for a subsequent listing of up to three additional fears/ worries if the informant indicates “Yes”. In order to examine less common and ASD-related anxiety presentations, which were not included in the existing SCAS-P scale items, the first and last authors coded and thematically organized caregivers’ responses to this additional item (see Thematic Analysis below for more details).

### **Thematic Analysis**

**Development of coding scheme.** Adapting from the thematic coding framework of Boyatzis (1998) and Crabtree and Miller (1999) and guided by existing research literature on both common and ASD-related anxieties (i.e. Bearss et al., 2016; Ozsivadjian et al., 2012; Kerns et al., 2014), we initially coded the responses as (a) informants’ elaborations to existing SCAS-P anxiety items; (b) ambiguous/ incomplete/ unclear responses which could not be clearly organized; and (c) valid responses for further thematic analysis. Responses from (a) and (b) were excluded from further analyses.

Responses in (c) were then further organized into ‘common’ or “ASD-related” fears and anxieties. DSM-5 diagnostic categories for anxiety disorders and the normative

developmental framework of common anxieties and fears in typically developing youth (i.e. Warren & Sroufe, 2004) were used as a coding framework, but we did not develop the coding system top-down (i.e. from the diagnostic manuals and literature). Rather, we used our knowledge of these to organize the themes of the codes for “common/ DSM” anxieties as derived by the participants. Responses coded as “unusual/uncommon” and/or ASD-related due to their content, nature or focus were given ASD-related codes. Despite having no formally established categories for fears and anxieties unique to the ASD population, themes that have repeatedly surfaced across existing literature (see Introduction; see also Magiati et al., 2017 for a comprehensive review) were used to guide the way we organized caregivers’ ASD-related responses into meaningful subthemes.

The first author pilot-tested the initial coding scheme with the first 150 responses. Further revisions and suggestions for improvement were made by the last author to create subthemes, which included both DSM-5 fears and anxieties (i.e., animals, social phobia, injuries), as well as common childhood fears that are not generally included in DSM but are well documented in the literature on children’s common fears, phobias, and worries. The first author then proceeded to code all responses from the database using the derived themes and subthemes (see Tables 2 and 3 for themes/ codes and subthemes/ codes). As written responses were mostly brief without elaborations or additional explanations, we adopted a more conservative coding approach and coded based on available information only, as we did not want to make assumptions about the underlying nature of the reported anxieties. For example, anxiety about “discos” most likely relates to audio or visual sensory anxiety. However, it could also be social or relating to being in a crowd. In the absence of any clarifications by the respondent, this was coded under specific “uncommon” phobias, and not under sensory or social).

**Reliability.** The last author then reviewed all codes to establish inter-coder reliability ( $k=.88$ ). Any disagreements were discussed until an agreement was reached. After consensus coding of any discrepant responses between the first and last authors, a second round of reliability was carried out to further ensure consistency in coding given that participants' responses were written (and thus could not be elaborated or clarified further). In the second round, the third author blindly coded a random 10 out of every 50 responses in the database to further confirm reliability ( $k=.91$ ).

## INSERT TABLES 2 & 3 ABOUT HERE

### Results

#### Data used for analyses

Of the 870 participants in the pooled database, 154 (17.7%) did not clearly indicate yes or no to the open-ended SCAS-P item 39 question "*Is there anything else your child is afraid of?*". Of the 716 who responded either "yes" or "no" to this additional item, 287 included at least one written response describing the type of worry/ anxiety/ fear that their children were experiencing (see Figure 1). Some participants provided only one written response, whilst others included two or more responses. Thus, a total of 545 written responses to the optional item 39 were obtained for analyses.

## INSERT FIGURE 1 ABOUT HERE

The 545 responses were first examined exhaustively and responses that merely elaborated on or provided specific examples to existing SCAS-P items were removed from further analyses ( $n=100$  responses), as the focus of the study was on identifying additional anxieties, fears or worries, not ones already mentioned in the scale; ambiguous/ missing responses were also removed ( $n = 133$ ; 24.4%). The remaining 412 valid responses (75.6% of the total responses) were then thematically organized into themes and subthemes using the finalized coding scheme outlined earlier.

### **Common and ASD-related Anxieties Reported**

**Common childhood fears.** Of the 412 valid SCAS-P 39 responses, just over half (220, 53.4%) were coded under “Other Common Childhood Anxieties” (symptoms and presentations which are generally common in neurotypical 6-18 year old youth). These included socially related fears (31.8%), common worries about being in danger (16.4%) and weather and natural environment worries (about 11.4%; see Table 4). Amongst socially related fears, performance and achievement-related ones were most frequently reported, followed by worries about social relationships and fear of punishment (Table 4).

#### **INSERT TABLE 4 ABOUT HERE**

**ASD-related anxieties/ worries/ fears.** The remaining 192 responses (46.6%) were coded as “ASD-related” and further organized into four main subthemes from most to least frequent: (a) sensory, (b) specific “uncommon” phobias (SUP), (c) fears about change/ novelty/ uncertainty, (d) anxiety relating to social/ language/ communication demands (see Table 5).

#### **INSERT TABLE 5 ABOUT HERE**

**Sensory.** Auditory-related fears concerning loudness of stimuli were the most frequent source of fear/ anxiety reported (e.g., “babies crying”, “(sound from) hairdryer”), followed by other specific auditory input (e.g., “sounds from water pipes”) and tactile-related sensory worries (e.g., “being touched”; see Table 5).

**Specific “Uncommon” Phobias (SUP).** There were four specific uncommon phobia subthemes: (a) specific stimuli were the most frequent, followed by specific (b) activities/events, (c) situations/places, and (d) people (see examples in Table 5). Under (a), further subthemes were developed: (i) other objects (e.g., drainage pipes and stickers); (ii) food (e.g., baked beans, chocolate chips), (iii) mechanical objects (e.g.,



vacuums, washing machines), and (iv) media/ movies (e.g., specific TV advertisements; see Discussion on sensory issues likely underlying several of these SUPs).

### **Association between Child Characteristics and Common versus ASD-related anxiety reporting**

For the purposes of these analyses, participants whose caregivers provided ambiguous/ incomplete responses and those who merely elaborated on existing SCAS-P items ( $n=51$ ) were excluded. Each of the remaining 236 participants with at least one valid/ coded response was grouped as “1” if their caregivers reported only common additional childhood anxieties in SCAS-P open ended item 39 (102/ 236 respondents; 43.2%) or as “2” if they reported at least one ASD-related anxiety (134/236 respondents; 56.8%).

A logistic regression analysis was conducted to ascertain the role of gender, age, overall functioning level, and autism symptom severity scores in predicting the reporting of none versus one or more ASD-related anxieties in SCAS-P item 39 group membership. The model was statistically significant,  $\chi^2(4, n = 113; 98 \text{ males}) = 11.03, p = .03$ , and explained 12.5% (Nagelkerke  $R^2$ ) of the variance, correctly classifying 56.4% of the cases. When all variables were considered together, caregivers of individuals with higher autism symptomatology were more likely than caregivers of young people with less severe ASD symptoms to report at least one ASD-related anxiety (see Table 6).

### **INSERT TABLE 6 ABOUT HERE**

### **Discussion**

This study aimed to better characterize common and ASD-related anxiety symptoms and experiences by thematically coding caregivers’ spontaneous responses to an open-ended SCAS-P item enquiring about additional anxieties, fears, and worries in a large sample of youth with autism. Furthermore, we explored whether individual

characteristics may distinguish between those who only reported additional common, versus those who also reported ASD-related, anxieties. Just over half of the responses to the SCAS-P open-ended item 39 were additional anxieties commonly present in childhood, with social worries most frequently reported. Just under half of the responses were ASD-related, of which sensory related ones were most frequently reported, followed by other specific uncommon phobias and worries relating to novelty/uncertainty/change. Participants with higher ASD symptoms were more likely to have been reported to experience at least one additional ASD-related anxiety.

The present study confirms and extends the limited, but growing, number of largely focus group studies (see Introduction) examining emerging themes of anxiety phenomenology in ASD. Our findings clearly support a profile of both common and ASD-related anxieties in young autistic people as reported by their caregivers, as was also found in Kerns et al.'s (2014) study using clinician judgment via modified clinical interviews (see also Adams et al., 2018 who identified common and ASD-related signs of anxiousness).

### **Common childhood anxieties**

Among common childhood anxieties reported by caregivers in SCAS-P item 39 (N=220 responses), but which were not included in the original SCAS-P scale, social worries were the most frequently reported common anxieties (N=70 out of 220 responses) in this population. These included being rejected, letting people down, being different, having no friends, or being punished for getting things wrong (see Tables 2 and 3). These fears and worries are common to many young people, but are not included in the existing SCAS-P social anxiety items. The recently developed Anxiety Scale for Children-Autism Spectrum Disorder (ASC-ASD) by Rodgers and colleagues (2016) does, however, include several items relating to these common social anxiety

experiences. For example, the ASC-ASD includes an item relating to worries about what others think of the young person (i.e. that he/she is different) and an item relating to worrying about making a fool of themselves in front of people. The frequency of similar, spontaneous mentions of such fears by the caregivers in the present study provides some validation for their inclusion in the ASC-ASD and other similar measures. Should other existing general anxiety measures be enhanced or adapted for improved use for youths with ASD, we recommend including more social anxiety items to evaluate several different aspects of social worries that are commonly experienced in autistic youths. In addition, our data also reported other worries for youth with and without ASD, especially regarding dangerous objects or experiences (i.e. getting lost, fire) and animals, which are not included in the SCAS-P (only insect phobias are included). Such items should also be explicitly considered for future ASD-friendly addendum subscales of existing measures, or explicitly enquired about in clinical questioning and interviewing.

### **ASD-related anxieties**

With regards to ASD-related anxieties (N=192 responses), sensory-related worries were the most commonly reported in our study (N=107 out of 192 responses; auditory anxieties occurred most frequently, followed by tactile-related anxieties). Specific “uncommon” phobias and worries about novelty or uncertainty made up the remaining caregiver responses (see also Kerns et al., 2014). Several of these are included in the ASC-ASD by Rodgers and colleagues (2016; i.e. item 5 relates to worries about being touched; item 9 about new things, people or places; item 21 about too loud, bright or busy places; item 23 about what will happen next or change of plans). The present study’s findings further support the addition of such items in an anxiety measure for youth with ASD.

Specific “uncommon” phobias (SUPs), which were the second most frequently reported additional ASD-related anxiety (N=56 out of 192 responses), are not explicitly included in the ASC-ASD or in any other anxiety measure to date. When closely examining the caregivers’ SUP examples in the present study (see Table 3), it becomes apparent that many of these are likely underpinned by sensory hypersensitivity and are probably sensory in nature (i.e. auditory or visual or texture/ tactile aversive sensory experiences associated with these specific stimuli become anxiety-provoking; examples include vacuum cleaners, discos, specific foods, etc.). In coding these items for the present study, however, we took a more conservative approach and coded them under specific “uncommon” phobias and not under sensory anxieties, as there was no clear or explicit mentioning of the sensory element of the stimuli in caregivers’ written verbatim responses. When such screening tools are used clinically, it would be important for clinicians to follow-up on checklist-reported information to try to further clarify the underlying nature of several of these specific “uncommon” phobic stimuli reported.

### **Factors Associated with the Presence of ASD-related or Common Anxieties**

Only one study to date has specifically examined predictors of common and ASD-related anxiety symptoms (Kerns et al., 2014) and they found that autistic symptomatology and anxious cognitive styles predicted ASD-related anxieties, while higher anxious cognitive style, better language ability, and higher hypersensitivity were more predictive of common (DSM-related) anxieties. Supporting Kerns and colleagues’ findings, higher autistic symptoms also predicted participants’ reporting of at least one ASD-related anxiety group membership in the present study, suggesting that these are more closely related to ASD experiences and symptoms than common/ DSM anxieties and providing support for conceptualization of distinct anxiety experiences underlined by

different correlates, and possibly mechanisms (see Ollendick & White, 2013; Kerns et al., 2014).

### **Strengths and Limitations of the Present Study**

The large sample size spanning twelve studies from three countries allowed for greater representativeness in terms of examining common anxiety profiles in ASD and power to sample even the less common anxiety experiences that might have been missed in some of the previous studies with much smaller sample sizes. The availability of measures of functioning and autistic symptomatology for many, although not all, participants enabled the exploration of possible associations between individual characteristics and ASD-related anxieties. The detailed thematic analysis allowed a rich, yet concise and structured, organization of themes and subthemes in both common and ASD-related additional anxiety experiences.

Several limitations are also important to note. Firstly, the SCAS-P item 39 used in this study is an optional additional item; thus, the lack of response by many of the informants cannot, and should not, be regarded as an indication of the absence of other common or ASD-related anxieties in these young people. Fatigue from completing the SCAS-P and other measures in most of the pooled studies in the database could, for example, lead to omitting or skipping the additional optional item. Secondly, due to the archival nature of the dataset and survey methods adopted, it was not possible to further clarify ambiguous or incomplete/single worded responses. However, consistent coding was observed in these responses and conservative coding was adopted by coding the most salient characteristics noted in caregivers' written responses, avoiding over-interpretation (e.g., fear of haircuts = tactile; discos = places<sup>6</sup>).

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<sup>6</sup> It is possible for example that a fear of discos is in fact sensory in nature (auditory), but it is not possible to be entirely confident that this is the case, as it could also be tactile or due to large crowds or for other reasons, i.e. uncertainty/ unpredictability/ visual sensory, therefore coding was more general in these

Furthermore, the brief written responses by the caregivers may not fully capture the extent, intensity, and impact of the distress experienced in relation to the reported fears/anxieties, nor do they specify if the anxiety is anticipatory or more reactive. It has been suggested (Kerns et al., 2014; Mayes et al., 2013) that fears and anxieties often reported as “unusual” by caregivers of young people with ASD are due to the “intensity, obsessiveness, irrationality, or interference with functioning” rather than necessarily idiosyncratic or atypical (Mayes et al., 2013; p. 153). Although respondents completed this open-ended item following a 38-item anxiety-specific measure, it nevertheless remains possible that their responses may capture not only fear-based experiences, but also potentially challenging or avoidant behaviors. These behaviors may not be primarily or entirely fear-originated, but may be more broadly upsetting or distressing. As the method adopted did not involve a face-to-face interview, it was not possible to clarify and expand on their responses to ensure they were anxiety-based only (see Kerns et al., 2017 for promising psychometric properties of an adapted addendum clinical interview aiming to do just that and to disentangle anxiety from ASD experiences). Similarly, it was not possible to disentangle, for example, anticipatory fear/worry towards sensory stimuli from stressed reactions to such stimuli. However, we argue that the way the question was phrased (“Is there anything else your child is really *afraid* of?”) does provide quite specific and clear focus of the question to most likely guide fear-based responses. Further, it remains possible that, had the question included the terms “worried about” or “anxious about”, the informants may have evoked more or different responses as when compared to the “afraid” terminology used in this item. At the same time, we note that many responses (i.e. social, health-related anxieties) appear to be predominantly worry-

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responses (i.e. in this case, specific “uncommon” phobias, places) to avoid making assumptions about the particular anxiety reported and its underlying nature.

related, suggesting that informants were not restricted by the term “afraid” to report specific stimuli/fears only.

### **Possible Implications and Future Directions for Research and Practice**

Our findings highlight two major limitations of instruments developed for the general population, when used with youth with autism. Firstly, a significant number of additional common childhood anxieties, which were often reported by caregivers of youth with autism in this study, are not sampled by the SCAS-P, or by other common general anxiety measures for typically developing children. Second, the present findings further highlight the observation that current existing tools are insufficient in sampling anxiety manifestations that are more relevant or specific to individuals with ASD; thus recent efforts to develop and/or validate more ASD-informed tools (Rodgers et al., 2016; Keen et al., 2017), or addendum scales (Kerns et al., 2014) are important and clinically significant. Initial pilot tests and preliminary psychometrics analysis have showed promising results for the ASC-ASD as a valid measure of anxiety amongst individuals with ASD (Rodgers et al., 2016). Such work needs to be continued and strengthened by revision of items, inclusion of additional items to tap on themes identified in the present and other studies, and further validation research studies. Existing measures, such as the SCAS-P, can be improved and revised by developing and piloting an addendum subscale for young persons with ASD, which should include questions asking about the ASD-related anxiety themes and subthemes identified here. Furthermore, although this study included many cognitively impacted participants with ASD, future studies should include well-characterized samples of young people with ASD and intellectual disabilities to better characterize the presentation and experiences of anxiety in this group and, importantly, to carefully distinguish it from challenging behaviors, general distressing experiences and other complexities.

Clinically, assessment of anxiety in ASD should aim to include routine probes and clarifications for both common and ASD-related anxieties using more comprehensive measures and lines of questioning. The themes, subthemes and codes developed in this study could provide a helpful clinical framework of types and groups of common and more ASD-related anxieties for clinicians to specifically enquire about, so that important indicators of anxiety are not missed.

Finally, existing interventions for anxious youth with ASD have often adapted CBT anxiety interventions for individuals without ASD by including social skills or other related components or making other content or delivery focused adaptations (Moree & Davis III, 2010; see also Kerns et al., 2016 and Rodgers & Ofield, 2018). Future interventions can benefit from developing and piloting conceptual frameworks to specifically target not just common/ DSM, but also ASD-related anxieties. This will likely require a more ASD-informed biopsychosocial assessment and formulation, and different mechanisms/ processes to be targeted and systematically explored. For example, worries relating to sensory sensitivities could be targeted through sensory desensitization, improving sensory self-regulation and via environmental supports or modifications to reduce or better manage sensory overload; anxiety relating to novelty and change could be improved through gradual respectful exposure to change, surprise and novelty, as well as via environmental adaptations respecting autistic individuals' need for preparation, planning, structure and transition support; and/ or through directly targeting rigidity and/ or intolerance of uncertainty via working to improve the use of a broader range of helpful thinking and behavioral repertoires in autistic people's anxiety management "toolboxes" (see Rodgers et al., 2017; 2018; White, Simmons, Gotham et al., 2018).

White et al. (2018) and Rodgers & Ofield (2018) both argued for the importance of identifying and investigating candidate mechanisms before evaluating clinical impact



in future intervention research in this area. White et al. (2018) proposed several candidate mechanisms (cognitive, positive and negative valence, social processes and arousal processes) to target and investigate in relation to anxiety and depression. We concur and further recommend that these processes are targeted and examined differentially for their mechanistic role in common/ DSM versus more ASD-related anxieties. For this to be possible, future intervention studies will need to more clearly describe and assess, identify, describe, develop, and evaluate mechanistic focused treatment targets not only in relation to DSM/common, but also ASD-related anxieties.

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## COMMON/ASD-RELATED ANXIETY AND ASSOCIATIONS IN ASD

**Table 1***Participant characteristics and statistics of the full pooled sample and this study's subsample*

Participant Characteristics		Full international pooled sample N = 870 unless otherwise indicated	This study's subsample (respondents to SCAS-P item 39) N = 287 unless otherwise indicated	Comparison Statistics
Age		M = 11.58 years (SD = 2.77 years)	M = 11.12 years (SD = 2.65 years)	t(1155) = 2.46, p = .01 Cohen's d = 0.17
Gender	Male	763 (87.7)	250 (87.1)	$\chi^2(1) = 0.07$ , p = .79 $\Phi = 0.008$
	Female	107 (12.3)	37 (12.9)	
Diagnosis	Autism/ASD	727 (83.7)	241 (84.0)	$\chi^2(2) = .68$ , p = .71 $\Phi = 0.02$
	Asperger's	111 (12.8)	33 (11.5)	
	PDD-NOS	32 (3.7)	13 (1.5)	
Autism Severity Measure <sup>7</sup>	Harmonized pooled autism symptom severity score	M = .41 (SD = .20) N=392*	M = .38 (SD = .19) N=137*	t(527) = 1.21, p = .23 Cohen's d = .15
IQ or Adaptive functioning <sup>8</sup>	IQ scores	M = 96.58 (SD = 20.36) Range = 13-144	M = 96.07 (SD = 19.70) Range = 40-125	t(371) = .18, p = .86 Cohen's d = .03

\*Actual sample sizes for each of the variables in this Table is indicated separately in the respective rows, as not all pooled studies/ participants had data for all measures.

<sup>7</sup> Obtained from different measures in different studies including the Social Responsiveness Scale, the Developmental Behavior Checklist Autism Screening Algorithm score (DBC-ASA), and the Social Communication Questionnaire; see Measures; harmonized by dividing each participant's total raw score by each scale's maximum score (see Magiati et al., 2017) to derive raw scores with a 0–1 range (higher scores = more ASD symptoms); not all participants in all studies had ASD symptom severity measures.

<sup>8</sup> Standardized IQ scores were obtained from different measures in different studies including the WISC; WPPSI; WIAT; Stanford-Binet; Vineland Adaptive Behavior Scales; not all participants had IQ or VABS standard scores available.

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		N=312*	N=61*	
Informants	Adaptive functioning	M = 58.82 (SD = 40.37)	M = 56.73 (SD = 39.40)	t(360) = .47, p = .64 Cohen's d = .05
	SS scores	Range = 0–171	Range = 0–147	
		N=239*	N=123*	
	Overall	M = 4.73 (SD = 2.20)	M = 4.1 (SD = 2.31)	t(66) = 3.07, p < .01 Cohen's d = 0.28
	“functioning”	Range = 1–8	Range = 1–8	
	classification mean	N=551*	N=184*	
	ranking score (1-8)			
	Mothers	651 (74.8)	241 (84.0)	
	Fathers	77 (8.9)	28 (9.76)	
	Both parents	8 (0.9)	1 (0.35)	
	Grandparents	1 (0.1)	1 (0.35)	
	Others	4 (0.5)	0 (0.0)	
	Not reported	129 (14.8)	16 (5.57)	

## COMMON/ASD-RELATED ANXIETY AND ASSOCIATIONS IN ASD

**Table 2**

*Other Common Childhood Fears and anxieties themes/ codes and subthemes/ codes of caregivers' responses to SCAS-P item 39 with examples*

Other Common Childhood Fears – Main Themes/ Codes	Sub-themes/ Sub-codes (if applicable)	Examples
Animals (not included in SCAS)		Pigeons/birds, worms and snails, blue whales, large animals
Social	Social Evaluation (perception)	Hurting other people's feelings, letting people down, being different, afraid of being looked at, when parents disapprove of behaviours
	Negative Social Relationship/Experiences	Bullies, name calling, being picked on, confrontations, having no friends, falling out with friends, not being loved, not fitting in due to alienation by peers, being rejected
	New/unfamiliar Social Situations	Strangers, joining new groups of people, approaching and speaking to new people, interacting with other children
	Performance/Achievement	Being late*, not completing tasks on time*, not knowing how to perform given tasks, preparing for exams, making decisions about going places, moving on to secondary school, forgetting things for school, not feeling in control
	Fear of Punishment	Withdrawal of privileges, angry authoritative figures, caning, being scolded
Health-related		Getting injections, germs, surgery, getting dirty, (sight of) blood, getting injured
Weather/Environment		Thunder, lightning, storms, hurricane
Danger		Fireworks, fire, getting lost
Fears relating to Media/News/Movies		TV and films full of violence and gore, horror movies, news
Existential/Supernatural		Death, space, world ending, war, zombies, future, monsters
OCD-related		Thinking certain things will make someone else die

## COMMON/ASD-RELATED ANXIETY AND ASSOCIATIONS IN ASD

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PTSD-related	Relives journey to A&E involving car crash
Other common fears or other ambiguous/ unclear anxieties	Fairground/run rides, mascots, no pocket money, things being stolen or lost

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\* These were coded as performance related social concerns, although it is possible they could be linked to rigidity relating to time/ schedules/ deadlines.

## COMMON/ASD-RELATED ANXIETY AND ASSOCIATIONS IN ASD

**Table 3**

*ASD-related Fears and anxieties themes/ codes and subthemes/ codes of caregivers' responses to SCAS-P item 39 with examples*

ASD-related Anxieties reported in SCAS-P 39	Sub-categories (if applicable)	Further subthemes (if applicable)	Examples
Sensory	Auditory (loud)		Loud and/ or high-pitched noises, hand/hair dryer, babies crying, carol singer
	Auditory (others)		Specific noises/sounds, sounds from water pipe
	Visual		Bright lights, bright colours
	Tactile		Being touched, water coming down through shower head, swimming
	Olfactory		Smells of eggs, garlic, tomato
	Others		Peacock feathers
Specific 'Uncommon' Phobias (SUP)	Situations/Places		Walking along a particular street, discos, shops, Hungary
	Activities/Events		Bowel movement, looking at the moon, school trips, Christmas
	People		Men, street cleaners, small children
	Stimuli	Mechanical objects	Washing machines, fans, public automatic flushing toilets
		Food	Baked beans, ginger, green food, chocolate and chips
		Media/Movies	Start of windows logo, media logo, advertisements on TV
		Other Specific Objects	Balloons, drainage pipes, buttons, stickers
Novelty/ Uncertainty/Change			Surprises in films, new things at home, the unexpected, Changes to routines/plans

## COMMON/ASD-RELATED ANXIETY AND ASSOCIATIONS IN ASD

**Table 4**

*Additional Common Childhood Anxieties reported by caregivers in SCAS-P open-ended optional item 39 (N participants with at least one reported common anxiety = 153; N responses = 220)*

Main themes/ codes for Other common childhood fears/ worries/ anxieties	Subthemes/ codes (if applicable)	N responses (%)
Social	Total Social	70/ 220 (31.8)
	<i>Performance/Achievement</i>	23/ 70 (32.9)
	<i>Negative social experiences/relationships</i>	16/ 70 (22.9)
	<i>Fear of punishment</i>	14/ 70 (20.0)
	<i>Perceived social evaluation by others</i>	10/ 70 (14.3)
	<i>New/unfamiliar social situations</i>	7/ 70 (10.0)
Danger related		36/ 220 (16.4)
Weather/ Environment		25/ 220 (11.4)
Animals (not included in SCAS)		23/ 220 (10.5)
Existential/ Supernatural		23/ 220 (10.5)
Health-related		20/ 220 (9.1)
Fears relating to Media/ News/ Movies		9/ 220 (4.1)
OCD-related		2/ 220 (0.9)
PTSD-related		1/ 220 (0.5)
Others/ambiguous/unclear		11/ 220 (5.0)
Total Other Common Childhood Fears		<b>220 (100)</b>

## COMMON/ASD-RELATED ANXIETY AND ASSOCIATIONS IN ASD

**Table 5**

*ASD-related anxieties reported by caregivers in SCAS-P additional open-ended item 39 (N participants with at least one reported ASD-related anxiety = 133; N responses = 192)*

Main themes/ codes for ASD-related anxieties reported	Subthemes/ subcodes (if applicable)	Number of responses (%)
Sensory	Total Sensory	107/ 192 (55.7)
	<i>Auditory (loud)</i>	65/ 107 (60.7)
	<i>Auditory (others)</i>	17/ 107 (15.9)
	<i>Tactile</i>	18/ 107 (16.8)
	<i>Visual</i>	3/ 107 (2.8)
	<i>Olfactory</i>	2/ 107 (1.9)
	<i>Others</i>	2/ 107 (1.9)
Specific 'Uncommon' Phobias (SUP)	Total SUP	56/ 192 (29.2)
	<i>Stimuli</i>	29/ 56 (51.8)
	<i>Activities/Events</i>	13/ 56 (23.2)
	<i>Situations/Places</i>	10/ 56 (17.9)
	<i>People</i>	4/ 56 (7.1)
Novelty/Uncertainty/Change		29/ 192 (15.1)
Total ASD-related Anxieties		<b>192 (100)</b>



## COMMON/ASD-RELATED ANXIETY AND ASSOCIATIONS IN ASD

**Table 6**

*Logistic regression of age, gender, OF and AS on predicting group membership of children with none versus at least one or more ASD-related caregiver-reported anxieties (n = 270)*

Variables	<sup>a</sup> $\beta$	SE	Wald test	df	p-value	<sup>b</sup> OR (95% CI)
Constant	.56	1.00	.32	1	.57	1.76
Age	-.12	.07	2.80	1	.09	.89 (.78 – 1.02)
Gender	.48	.60	.63	1	.43	1.61 (.50 – 5.21)
Autistic Symptomatology	2.77	1.19	5.44	1	.02	15.92 (1.56 – 162.88)
Overall Functioning	-.12	.09	1.64	1	.20	.89 (.74 – 1.07)

<sup>a</sup>  $\beta$  values are the estimated unstandardized regression coefficients; <sup>b</sup> OR indicates likelihood of caregiver reporting at least one ASD-related anxiety

## COMMON/ASD-RELATED ANXIETY AND ASSOCIATIONS IN ASD